



The experiences of transgender and non-binary children and young people and their parents in healthcare settings in England, UK: Interviews with members of a family support group

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ABSTRACT

Background: Transgender and non-binary children and young people and their parents in England, UK are poorly served across a range of healthcare settings. Whilst UK equalities legislation and international guidance on transgender healthcare pathways protects this group from discrimination and mandates an affirmative approach, services in England are not keeping pace.

Aims: This study aims to draw on the experiences of transgender and non-binary children, young people and their parents in a support group in England in order to investigate their experiences of healthcare provision, and to develop some ideas for improvement.

Method: Data was collected with participants in a family support group which offers a parent helpline service, social groups for children and parents, and training for schools and other organizations. 65 parents and children from 27 families from the family support group attended participatory workshops where they were given a range of briefs: “health,” “family,” “friends,” and “education.” Their participation involved being asked to define their own interview questions and collect data by interviewing each other. Their interview notes constituted the raw data. Data was coded inductively by the author with respondent checking as a second stage.

Results: Results constitute the views of a small group of people, so cannot be generalized. However, they do illustrate some of the issues which may arise. Participants’ experiences elicited five key themes: professionals’ perceived lack of clinical and therapeutic knowledge; mental distress caused by excessive waiting lists; professionals’ stereotyped gender assumptions; direct discrimination within healthcare settings; and a lack of attention to parent and child voice, especially in terms of school-based experiences and where a patient had a diagnosis of autism.

KEYWORDS

Deadnaming; healthcare; misgendering; non-binary; parents; practitioner; school; transgender

In the United Kingdom (UK), the United States (US), and elsewhere, transgender and non-binary children and young people have increasingly been presenting at both generic and gender identity-related services in the healthcare system (Kavalanka, Weiner, & Mahan, 2014; Pearce, 2018). In England, UK, physical and mental healthcare is provided to transgender and non-binary young people by primary care physicians (family doctors, known in the UK as general practitioners, or GPs). These young people are often initially referred to Child and Adolescent Mental Health Service (CAMHS), although this is not a requirement. There is a sole specialist

gender development service (GIDS) for children and young people in England. Young people can self-refer to GIDS, or be referred by CAMHS or by their primary care physician. This research asks: how do transgender and non-binary children, young people and their families in one support group in England experience healthcare provision?

This study, working with participants from 27 families from the North and South of England in the UK, was conducted within (but not funded by) a family support group (FSG) for transgender and non-binary children and young people and their families. The FSG offers training to

organizations, workshops and seminars for families as well as the mutual sharing of experience through social events, enabling the parents of older children to mentor those of younger children, and for older transgender and non-binary children to mentor younger ones. This kind of group support can be an important and healing resource for parents (Aramburu Alegría, 2018; Capous-Desyllas & Barron, 2017; Kuvalanka et al., 2014; Malpas, 2011). Of significance to the focus of this paper, the group is inclusive of children with autism spectrum disorders (ASD); this population is thought to be constitute around 7% of transgender young people (Kuvalanka, Mahan, McGuire, & Hoffman, 2018; May, Pang, & Williams, 2017).

Numbers of young people recognized as transgender and non-binary appear to be rising, but figures from different countries vary widely. Significantly, in the UK there is no official record (Pearce, 2018). Malpas (2011) reports that one in 500 young people in the US can be identified as transgender. May et al. (2017) report that 1.2% of the US population may have gender dysphoria. Research with a randomized sample of just over 8000 secondary school students from New Zealand identified 1.2% who reported being “transgender” and a further 2.5% who reported being “not sure about their gender” (Clark et al., 2014). As in research by Zucker et al. (2010), this qualitative study aims to illustrate these statistics with a limited sample of individual experiences.

Previous research into transgender and non-binary young people’s experiences of healthcare in the UK suggests that they tend to avoid primary healthcare because of the dysphoric feelings induced by their anticipation of gender non-affirmative experiences (Fae, 2018; Harris, 2018). This includes dental care (Aramburu Alegría, 2018). Harris (2018) suggests that school nurses have a role in supporting access to healthcare for transgender and non-binary young people in the UK, although this resource is now less available due to funding cuts across the education and health sectors. Initial attempts to gain access to appropriate treatment via the GPs who offer primary care in the UK can be fraught with financial, discriminatory, and knowledge barriers (Children’s Right Alliance for England (CRAE),

2016; Fae, 2018). The Children’s Rights Alliance for England (Children’s Right Alliance for England (CRAE), 2016) collected children’s views on transgender issues for the United Nations Committee to the UK, which subsequently raised concerns about trans young people’s healthcare with the UK government. However, most of the research on transgender and non-binary children and young people’s experiences of healthcare has been conducted outside the UK. In the US, Hoffman, Freeman, and Swann (2009) surveyed more than 700 LGBTQ youth and found that they valued healthcare providers who had good interpersonal skills and cultural sensitivity, and who understood them within the context of their developmental stages. Their research suggests that better training is needed for practitioners working with this group, particularly in terms of more collaborative working with the home and family; this is also the conclusion of literature reviews by Tellier (2019) in Canada and Coker, Austin, and Schuster (2009) in the US. Tellier (2019) found a range of evidence of transgender youth avoiding treatment for unrelated conditions and preventative healthcare in Canada, with Clark, Veale, Townsend, Frohard-Dourlent, and Saewyc (2018) confirming that non-binary youth between 14 and 25 were also affected, and pointing out that this particularly affected those living in rural areas. Goldenberg et al. (2019) note that Black transgender and gender nonconforming youth, who face specific difficulties in accessing adequate healthcare in the US, were more likely to access primary care services if their gender was affirmed. Transgender youth using healthcare facilities were found in separate pieces of research by Breland et al. (2016) in the US and Children’s Right Alliance for England (CRAE) (2016) in the UK to have experienced problems accessing puberty blockers, and a general sense that some practitioners were under-trained when it came to working with this group. This is of concern given a body of research confirming that blockers can be useful and well-tolerated when offered with supportive psychological therapies to help young people to gain some time develop their thinking around their gender identity (Lynch, Khandheria & Meyer, 2015; Sansfaçon et al., 2019; Schei Jessen & Roen, 2019; Zucker et al., 2010). As

Tellier (2019) also found, trans young people are often misgendered and experience a general lack of coordination of care with other institutions tasked with caring for adolescents, such as schools. There are many areas within which the existing literature suggests that parents and healthcare practitioners could garner positive results through collaborative working. Hillier and Torg (2019) report on the efficacy of a clinician-led FSG in the USA, and suggest that parents' voices are important in developing ideas about how healthcare providers might better support these children and their families. Kuvalanka et al. (2018) looked at healthcare for transgender and non-binary children and young people with ASD, concluding that professionals in each of these two apparently disparate specialities should collaborate closely to support better therapeutic input for gender-nonconforming children and support for their parents. Oliphant et al. (2018) in New Zealand outline a range of best practice guidelines for primary and other healthcare which recommend equitable, accessible gender-affirming care which is informed by international standards, evidence-based literature, and service-user voice. They outline clear approaches to collaborative working with parents, and foreground the need to be aware of youth-specific healthcare issues such as bullying, drug use and the pace of puberty. Many parents, pediatricians and psychotherapists working with transgender and non-binary children agree that it is important to collaborate with each other to assist social transition in physical and emotional safety at home and at school (Capous-Desyllas & Barron, 2017; Kuvalanka et al., 2014; Malpas, 2011).

In terms of the healthcare system for trans people in the UK, models of care are slowly emerging from a binary model to a more nuanced one, open to non-binary gender identities, particularly when it comes to care for adults (Pearce, 2018). This is in line with broader changes: it is becoming accepted in UK adult services and for children and young people outside the UK that whilst binary concepts of gender underpin the idea that any kind of variance is problematic (Kuvalanka et al., 2014), a depathologised, affirmative model of care is increasingly becoming the norm. In 2018, the World Health Organization confirmed that it

intended to reclassify "gender identity disorder" in its forthcoming International Classification of Diseases catalog (ICD-11, for implementation in 2023), changing it from a "mental disorder" to a "condition" (Beek et al., 2017). In making this change they cited a wish to reduce stigma and increase access to healthcare (France-Presse, 2018), although in states without free healthcare programs there was some concern that this could result in restricted access to treatment (Beek et al., 2017). The UK's 2010 Equality Act ostensibly aligns with this approach, protecting people from discrimination and encouraging understanding of those with the characteristic of "gender reassignment" (clumsily worded, but clarified as referring to anyone who has taken steps towards changing their gender, for example a name change). Despite these changes and legal protections, the findings in this research suggest that the development of adequate healthcare services for many trans young people in England does not appear to have kept pace. In 2018 the UK Government Equality Office released an LGBT Action Plan, with the stated aim of beginning to address the needs of LGBT people across the UK. Whilst it did promise a forthcoming and long awaited guidance document for schools about supporting transgender young people (at the time of writing, still awaited), it has been widely criticized for failing to signal much-needed changes in healthcare for trans people under the age of 18 (Children's Right Alliance for England (CRAE), 2016). Similarly a 2018 review of the UK's Gender Recognition Act (2004) did not invite comment on lowering the age limit for gender self-identification below eighteen, and non-binary people are as yet unrepresented in UK government policy documents.

This study is important at this time partly because as confirmed by the United Nations Committee (Children's Right Alliance for England (CRAE), 2016), the UK trails behind many other countries in the speed and efficacy of provision for child and adolescent gender affirmative healthcare (Children's Right Alliance for England (CRAE), 2016; Pearce, 2018; Vincent, 2018), and partly because of the unprecedented amount of negative attention from both mainstream and social media prevalent at the time of writing and focused on transgender and non-

binary people, especially young people (Fae, 2018). To redress the imbalance of power, it is recommended that research into the healthcare experiences of trans youth should be conducted in collaboration with trans youth (Adams et al., 2017). This research contributes a participatory investigation of the experiences of healthcare provision for transgender children, young people and their parents in England. Drawing on a participant-researcher model (Carlile, 2012, 2016), this paper describes an attempt to invite transgender and non-binary children, young people, and their families attending a support group to contribute their expertise-by-experience towards discussions on improving the healthcare provision available to them in England.

Theoretical approach

As well as supporting the development of better healthcare services and reducing stigma for transgender and non-binary people, research with this group about their experiences challenges structuralist models of gender, and situates gender dysphoria as a public issue rather than solely a private trouble (Mills, 1959). This premise reframes “gender dysphoria,” which is situated within the gender non-conforming person, as at least partly attributable to “social dysphoria”- that is, a dysphoric pain resulting from the non-empathic response of others to a person’s perceived gender presentation or expression. An analysis of this kind prompts philosophical exploration by bringing together poststructuralist ideas with embodied experience: as Elling-Marchartzki (2017, p. 258) elaborates, sex and gender is both “dynamically embodied” and “discursively constructed.” The experiences of the transgender and non-binary children, young people and their families in healthcare settings related here demonstrate the negative impact on their mental and physical health of the “minority stress” (Hendricks & Testa, 2012) they experience.

Methodology: Research participants as experts on their own lives

As a lesbian and a mother I have experiences of LGBTQ+ spaces and groups and in supporting and understanding my now adult non-binary child.

But I am cisgender, and do not share the lived experiences unique to transgender and non-binary communities. The research methods I use therefore draw on the notion of participants as experts on their own lives (Kuvallanka et al., 2014). This work requires care around the use of language, and avoiding what Vincent (2018) describes as the “iterative linguistic microaggressions” (p. 107) which could impact on a transgender or non-binary person’s sense of safety and acceptance. In line with Vincent (2018) and other studies in this area (Birnkranz & Przeworski, 2017), this paper will be using the term “transgender” to refer to people who identify as other than the gender identified at birth, and “non-binary” to refer to people who identify outside the binary system of gender identification. Caudwell (2014) notes that the term transgender can apply to both “gender conformers” (who transition from gender identity A to gender identity B) and “gender transformers” who cluster more around binary-subverting genderqueer and/or non-binary paradigms. Where possible, this paper recognizes this diversity of identities, and also uses “trans” as an umbrella term covering a range of transgender and non-binary people, whether in receipt of a clinical “diagnosis” or not (Pearce, 2018). “Transgender and non-binary” is not a catch-all phrase. However, in the data, the respondents themselves did not usually distinguish between the two when they were talking about their experiences. The paper focuses specifically on trans identities but “LGBT+” and variations of this acronym are quoted in the data where respondents and other writers have used it. LGBT+ is understood for the purposes of this paper to mean lesbian, gay, bisexual, transgender, and anyone else who fits within or around these categories- potentially including people who are intersex, queer, asexual, and pansexual, for example.

It is particularly salient for researchers to pay attention to the emotional labor inherent in asking transgender and non-binary young people and their families to participate in research about their lives and experiences (Vincent, 2018). Approaching research with trans people and their families therefore requires “an ethics of care” (Vincent, 2018, p. 105). Clark et al. (2014) propose a therapeutic approach with trans young people that develops resilience, social skills and

emotional growth: participant-led data collection is similarly a relational and interpersonal experience, and the work described here has been conducted with this in mind. Participant involvement in research can offer reassurance and insights to both participants and researchers, and can be empowering to participants (Adams et al., 2017; Vincent, 2018).

Research with families draws on the fruits of intergenerational expertise (Carlile & Paechter, 2018). Parents can be knowledgeable; many have researched and read much about trans children (Kuvallanka et al., 2014, 2018; Malpas, 2011). Children and young people also often conduct their own extensive research, especially online (Carlile & Paechter, 2018). In addition, the idea that children might be experts on their own lives is not only accepted but has long been seen as ethically and empirically crucial in much of the research emerging from the disciplines of health, education, social work, and youth work (Carlile, 2012, 2016; Fielding & Bragg, 2003; Hart, 1992; Rudduck & Flutter, 2003; Sansfaçon et al., 2019). This approach to youth voice, however, does not seem to have become embedded in the healthcare experiences of trans and non-binary children and young people in England, as noted by United Nations Committee members inspecting children's rights in the UK (Children's Right Alliance for England (CRAE), 2016). NHS England released a five year "Forward View" document in 2014; in response, the British Youth Council released guidance on how to ensure youth voice is embedded in healthcare in England. Conducted in 2019, this research offers evidence that although it is acknowledged to constitute useful practice (Sansfaçon et al., 2019), for trans children and young people and their parents, "voice"-informed healthcare is still rare.

The project described here sought to investigate the experiences of trans children and young people and their families in their interactions with primary and secondary healthcare providers in England. The findings outlined in this paper emerged from two participation-researcher workshops conducted with FSG families at a Saturday drop-in event and at one of the residential weekends arranged by the organization. The data here is therefore drawn from a small group of people

and cannot be generalized. Recruitment was via a support group, so it must be recognized that respondents may have been biased by their shared involvement in seeking support. However, the study does illuminate the experiences of some transgender and non-binary children, young people and their families.

Participants

This research was conducted with 65 people across 27 families. Around half the respondents were adults; the remainder were young people aged between twelve and eighteen. Four of the participating parents had children under twelve. Most of the adults were cisgender parents and around two thirds were women; one was a non-parent FSG volunteer who identified as a trans man. All of the participating children and young people were transgender or non-binary, with around two thirds recorded as female at birth. The FSG is inclusive of children and young people with autism spectrum disorder (ASD); seven of the families involved in the research had transgender and non-binary children with ASD diagnoses. Monthly FSG drop-in sessions and quarterly residential weekends are provided free or at an affordable rate to enable participation for all: the parents' professions range from social worker and teacher to quantitative analyst, school lunchtime supervisor, club singer, and child-minder (home-based daycare worker).

The Illuminate participant-researcher model

The participant-researcher model used here is called "Illuminate" (Carlile, 2012, 2016). It essentially presents workshop participants with a brief, and then supports them to develop their own interview questions and to carry out data collection by interviewing each other right there in the workshop. Illuminate has been subject to publication and peer review, and has formed part of a large international funded research project (Anderson & Macleroy, 2016) as well as being trialed and refined in over 25 schools, charities, and community organizations. It is essentially a model designed to involve participants in data collection from many angles: to get beyond "glib

responses” to more profound insights; to draw on participants’ expertise in formulating interview questions; and to involve participants in the gathering of data. In its approach to facilitating constructive collaboration between organizations and the people who use them, it is a mediative approach, designed to maximize the potential for research findings to change structural inequities and to inform institutional policy and practice (Carlile, 2013).

From discussion briefs to emerging themes

An Illuminate project starts with a brief chosen by the organization. In this case, a range of briefs were chosen by the FSG, including: “health,” “family,” “friends,” and “education.” Whilst these briefs may play a part in informing later data analysis, they would not rigidly frame the emerging themes, but were designed to elicit findings across the range of issues that the FSG as an organization considered to be important—hence ensuring their commitment to meaningful interest in the results.

With all Illuminate projects, it is important to support the participants (service users, students, or community members) to come up with their own data-collection questions and to manage the expectations of those in power (service managers, teachers, or charity managers) who had supplied the briefs for the project. It was therefore important to explain to FSG staff that the themes which would eventually emerge from the process may have, in a discursive sense, traveled some way from the original five briefs. In fact the six themes generated by the FSG Illuminate workshop participants did indeed develop the original briefs into an overlapping but somewhat transformed set of foci. These included: “the trans child and their family”; “the mental health of trans young people”; “physical health and exercise”; “experiences of healthcare providers and treatment”; and “school,” including social, curricular and pastoral concerns. The qualitative methods employed to draw these themes from the data are explained below. The work reported in this article refers to a subsection of the data relating to experiences of healthcare settings, and

mostly emerged from groups addressing the briefs of “health,” “school,” and “family.”

The Illuminate workshop

The workshop begins with the presentation of discussion briefs to participants. It is key to the process that the briefs are not questions, but single words or phrases designed to elicit participants’ own ideas. The approach supports participants to look in depth at the briefs, develop data-collection questions of their own, and collect interview data from each other to answer those questions. The process is guided by a set of forms. In an Illuminate workshop, participants write discussion notes and interview questions and responses on the forms, and these notes become the raw research data.

In this case, the sessions each lasted about 120 minutes. At the FSG residential weekend, there were about 40 participants in fifteen families including trans young people and adults, cis-gender siblings, parents, carers, and volunteers, seated round tables in seven groups. At the Saturday drop-in, there were about 25 participants in twelve families, seated in four groups. The groups were partially self-formed, although in order to encourage a range of age-specific discussions, parents were encouraged to sit together, and young people to sit within their own groups. Parents did not sit with their own children. The sessions began with introductions and a discussion ensuring informed consent.

Following the informed consent discussion, each participant was given a standard Illuminate “Getting to a Question” form. Using the forms in their small groups, workshop participants brainstormed the meanings, questions, thoughts, and ideas stimulated through a discussion of each brief. Through the guided process, they refined their thinking into a range of interview questions.

The next step requires participants to interview each other in the workshop. They draw on the notes and questions recorded on their “Getting to a Question” forms to help them design a set of five to eight open interview questions. Participants interviewed each other first within their small discussion groups, partly to collect data, and partly to refine their interview

questions. They were then invited to find someone in another small group in the workshop to interview, using the same (albeit refined) questions. Each interview was therefore conducted with at least two respondents. During their interviews, participants are asked to write down as many verbatim quotes as possible. Along with the “Getting to a Question” forms, all sets of interview questions and the responses written down form the body of data collected at the end of the workshop. The process is noisy and messy and not everyone participates in each step, but this is built into the model: Illuminate workshops are designed to work flexibly with a range of people, abilities, and interests, and tend to produce a good level of data in a relatively short amount of time.

Developing themes and subthemes from the briefs: Methods of analysis

At the end of the two FSG Illuminate workshops, around twenty notated “Getting to a Question” discussion forms and around thirty five interview forms were collected, complete with their questions and responses. Later, the forms were read through to gain a broad overview of content and then themes and subthemes which emerged consistently across the groups were identified. These themes were outlined and evidenced in a workshop report document and FSG parent volunteers were invited to give feedback. Subsequent analysis was refined by this feedback. The thinking behind the data analysis was inflected by the initial briefs and informed in part by the literature summarized above, but was primarily concerned with avoiding researcher bias by allowing the participants’ own voices and ideas to emerge.

Through this process, the themes under which the “Results” section below has been organized materialized under a variety of the original briefs provided in the workshops. For example, the groups which had the briefs for “health” and “family” both discussed the impact on trans children of the relationship between healthcare providers and parents or carers, so this data was filed under the theme for “The trans child and their family.”

Ethics

All workshop participants read an information sheet (or according to need, had it read and explained to them), and signed a consent form. These materials have been designed in line with the guidelines of the British Educational Research Association and agreed by an ethics committee at the author’s university. Confidentiality is maintained by the exclusion of names in this article. Given the hostile media environment surrounding trans children, young people and their families in the UK, where necessary, special care has been taken to change other identifying details.

Illuminate has been designed as a data solicitation methodology which is responsive to content matter which may be sensitive. In allowing participants to develop their own interview questions, the method gives control of the subject matter to the participants. Recognizing the work involved in data collection, Illuminate also aims to exchange participation for skill development. It is therefore designed to help respondents learn and practice transferrable speaking, listening, writing, critical thinking, and analysis skills at the same time as their participation in the research (Carlile, 2012). It is designed on the basis that people of all ages are experts on their own lives and experiences. It is built on the dialogic and critical consciousness-raising models of pedagogy and research developed by Freire (1968) to redress the power imbalance which can arise between people of different subjectivities (teacher and student, researcher and researched, or doctor and patient, for example).

Results

The overarching sense emerging from the FSG workshops was the dissatisfaction, frustration, and distress both parents and children or young people felt with healthcare providers- both primary carers and gatekeeper referrers such as GPs and CAMHS, and the specific gender-focused GIDS provision itself. The NHS in general is very highly regarded and appreciated in the UK, and some respondents were able to recall interacting with some helpful staff members. However, the experiences summarized below were identified by

workshop participants as key sources of the mental ill-health and distress experienced by both trans young people and their parents. They emerged strongly through the collaborative Illuminate process as clear themes.

The results section starts with an overview of the impact of healthcare experiences on the trans child in the context of their family; including parents' and siblings' need for support. The section goes on to address the mental health of trans young people and how they experience discussions between clinicians and parents. Many practitioners were felt by the families to have been under-trained, and as a result to lack adequate knowledge of appropriate clinical research. Participants also discussed painful misgendering and deadnaming experiences which they ascribed to a lack of education about gender identity issues. This, together with waiting list times and lengthy treatment pathways; disregard for service user expertise, particularly in relation to what might help at school; and a lack of patient and family input into clinical and therapeutic planning was found to have a negative impact on the whole family. These effects were often magnified in situations where the trans child also had an ASD diagnosis.

Parents' and siblings' need for support

As one parent in the workshop explained in her discussion notes, "family support is of paramount importance to the young trans person for acceptance, help, support, and friendship. All need to be united and well-informed." However, despite this, the FSG parents' mental wellbeing was often described as being undermined by their relationship with CAMHS (Child and Adolescent Mental Health Services). Parents in the Illuminate workshops characterized their relationship with CAMHS and GPs (general practitioners; sometimes known as family doctors) as one of "struggle." It is worth noting here that GPs and CAMHS are not gender specialists, but generalists in the area of healthcare and child and adolescent mental health respectively. Most parents felt that they were battling healthcare services for adequate support for the whole family, with many talking about how the whole household

was experiencing mental and emotional distress. One of the workshop parent participants recounted a difficult family weekend away where her trans child was "trying to stab himself with a knife" and his cisgender sibling also cut her arms with a piece of plastic. She said that when they returned home, she "just felt flattened." Another parent, a father, talked about the need to include parental mental health and family dynamics in future research about trans children and young people, explaining that he felt he was seen merely as the person who brought his child to their appointment, and asserting: "we are patients too."

Parental expertise

Many of the parents in the session had considerable knowledge and understanding of the issues and concerns surrounding the care and support of trans children and young people, partially derived from their experience with their own trans children, and partially from their professions, prior experience, and independent research and reading. One parent who was a social worker received support from her workplace. She was able to mitigate against the effects of the long wait for CAMHS input (before a potential referral to GIDS was even contemplated) by drawing on her own social work skills to do reflective "journal work" with her child at home. However, this kind of expertise was not often acknowledged or called upon by professionals in the healthcare appointments she attended with her child.

Clinicians' advice to parents

An area of frustration for the FSG workshop participants related to the advice some GPs and CAMHS practitioners gave to parents and carers. Examples which participants shared included advice not to take a child's thoughts on their own gender seriously; or to ignore or punish self-harming behaviors relating to body dysphoria. The parents reported that this was counter to what they had read in their investigations into best practice, so often led to confusion. It can also cause disagreements between parents and their children, leading to a loss of parental support. In her workshop notes, one FSG parent-volunteer described a helpline phone call with another parent asking for

advice about their family's experience with the Gender Identity Development Service (GIDS) clinic:

The professional refused to refer [her trans son] on to adult services because he was "too feminine." He went to his own GP but the [young people's GIDS clinic] had advised them not to refer. So he has not got access to the adult GIC [Gender Identity Clinic]. The parents' support (or lack of) has been influenced as they have faith in the professional's opinion. The young person's ability to consent and make informed decisions is not being heard.

A lack of adequate information

Some of the workshop participants - both cisgender parents and trans young people - partly ascribed problems with their mental wellbeing to the lack of information and research available from GPs, CAMHS practitioners, and the children's and young people's Gender Identity Development Service (GIDS) on important issues such as medication. Parents and young people in the workshop particularly mentioned the lack of adequate knowledge about the research available on cross-gender hormones and blockers from both endocrinologists and from other GIDS and primary care practitioners. One fifteen year old participant said that he had been told at one time that six months of testosterone would be enough to remove any chance of reproduction using his own biological material, but he had noted that clearly there were trans men in the media who had become pregnant and given birth after more than six months on testosterone. This lack of clarity was a source of considerable distress. He asked for practitioners who were knowledgeable enough to share "actual research on hormones for trans people ... actual studies on delaying hormone treatment and impact on mental health," adding "... give us statistics!"

Misgendering and deadnaming

Many of the workshop participants described being misgendered when they interacted with their family doctor (GP), both for a non-gender-related appointment and when approaching their primary care practice to request a referral for GIDS.

Misgendering can be direct, or can be caused by deadnaming- calling the person their previous gendered name- which if done in public has the effect of "outing" them. For three of the workshop families, the misgendering and deadnaming happened in a busy waiting room, in front of other patients and their caregivers and families. One young transgender man in the workshop said that being misgendered by his GP led to him being "denied the right to have a referral," and being "advised that I would be ok after therapy, which resulted in a decline in mental health." He also felt "like an outcast, not a valid member of society worth listening to ... I stopped work. I nearly felt like giving up." He was recently misgendered again at a new GP surgery. He said: "I felt vulnerable when this happened ... totally exasperated. Like, "really?!" And a letter from my GIDS clinic which had previously been correct reverted back to my previous name." This experience of deadnaming caused him to feel "invalidated, worthless, judged, and frustrated." Many workshop participants felt that healthcare staff had been under-served by their training providers, particularly on misgendering, deadnaming, non-binary people, and stereotyped ideas about gender presentation and expression.

Lack of training and understanding about gender issues, and the impact on families

In the experience of some of the young people in the workshops, the lack of training for healthcare staff led to stereotyped assumptions about their gender, and a lack of adequate treatment. For example, when one young transgender woman attended an appointment wearing jeans and trainers, she was described by her GIDS practitioner as "not serious" enough to warrant support for clinical intervention. One parent who is also a paid trainer for the FSG worried about the impact of "uneducated professionals' lack of knowledge, understanding, and poor use of language" in schools, social services, and the NHS on family relationships, mental wellbeing, and physical health. One parent described how CAMHS "... were supposed to be helping with [the child's gender identity] and anxiety but because they had no trans knowledge they only treated the anxiety, leaving the family unsupported on the trans issue." Once back at home,

“... anxiety increased, as the CAMHS worker was not addressing the trans issue.” Consequently [there was] increased anxiety before each appointment, causing stress for the family.” The impact on the family manifested in feelings of tension and being “overwhelmed.” The whole family “... began to avoid places and situations which caused tension” and the parent became increasingly “frustrated.”

Waiting list times and lengthy treatment pathways

Several parents in the workshops questioned the economic logic applied to waiting list management, reasoning that the short term cost savings of seeing fewer patients might result in more expensive longer term mental health needs. One felt it was important that service providers should look at “the impact and consequences of waiting lists on trans people’s lives and outcomes.” They felt that waiting times can negatively affect family dynamics. A parent of a seven-year-old child described how for their family there was “no provision from CAMHS” relating to trans issues due to a several months long wait for a place on the waiting list for an assessment for a referral to the GIDS, which she knew had its own long waiting list- up to eighteen months. She “was told by CAMHS to self-refer to a charity (FSG). That was two months ago- we are still waiting.” Because of the wait, her child “feels insecure and is unhappy.” Several other parents reported being referred by CAMHS to the FSG charity for support while they waited several months for the next available appointment. As referrals to GIDS can come directly from GPs, or even from young people themselves, this added waiting for CAMHS can often seem particularly fruitless.

Almost all of the FSG workshop participants who had been to the GIDS reported experiences where lengthy timeframes were applied in an arbitrarily universal manner- for example, certain medications were given for a set period of time before the child could move on to the next stage according to the clinic’s policy, despite the child’s age and stage of puberty at the start of the time period and without applying nuanced clinical reasoning for each individual. They thought that it

would be better if these policies were research-informed and specific to each child’s needs. A triage system trial was suggested by some parents to try and work out how best to prioritize children and young people in need of faster input.

A lack of collaboration with service users and other organisations (such as schools) into clinical and therapeutic planning

The participants in the workshops – both parents and young people- reported scant or tokenistic efforts to include their voices in treatment planning and service provision. There was in particular a dearth of collaboration between the healthcare practitioners, parents, and with the schools of the trans and non-binary children accessing healthcare services. One young person with autism in the workshop described school as being “loud,” with “lots of stupid people” in “small spaces- I hate small spaces or rooms with lots of people.” Many of the young people felt frustrated with their schools’ lack of understanding. One described “teachers being weird” and also mentioned how “splitting boys from girls” was problematic: “I’m non-binary so it felt wrong.” Another young person said that because their school refused access to appropriate toilets she had spent an hour every lunch time walking down the road to the local university to use their facilities. Many of the young people in the workshop also identified the fact that there were little or no LGBT+ people or issues featured across the school curriculum. This led to feelings of insignificance and invisibility, and was particularly noticeable within the super-gendered arenas of physical education and sex education. One young person wrote: “I didn’t know what ‘trans’ meant until I was 15. I grew up in a sheltered/ conservative area. If trans and LGBT+ issues were mainstream, I would have realized at a younger age. This would have saved a lot of time and distress.” Another young person said that if he had had earlier education about LGBT+ issues he “would have known sooner” and been “less stressed about life in the future.” He said that “it’s not ok for LGBT+ people to go through puberty if they don’t know what’s going on.” One felt that the information should not be

“hidden away from kids” and that “children are very open to things like this- it’s better to teach them early when they are more likely to understand.” The school context illuminates the need to listen to service-users: they are the only people who spend time in the home, healthcare and school settings.

As well as school-based experiences exacerbated by both being transgender or non-binary and autistic, some workshop participants talked about how the combination of diverse gender expression and autism was inexplicably bewildering for healthcare practitioners. They felt that the presence of an autism diagnosis tended to slow down clinical and therapeutic input on their child’s gender identity still further. One parent talked about how her daughter’s referral for ASD had neglected to mention the fact that she was trans. The GIDS referral, submitted a few months later, had nothing about her autism diagnosis on it. This student, aged eight and in primary school, had a particular wish to continue using the teachers’ toilet facilities as she transitioned into the next year’s class. She had been allowed to use them as a younger student as a support strategy to deal with as a noise-related anxiety associated with her autism. When she socially transitioned to female, the school, exhibiting a supportive approach, assumed she would want to use the girls’ toilets. She refused: she still had her noise-related anxiety; this was nothing to do with her gender. Her mother explained that if the healthcare practitioners who had undertaken her GIDS and autism diagnoses had collaborated with each other and the school, it may have prevented a considerable period of discomfort for this student.

Discussion and limitations

Discussion

The research participants related a consistent sense of disempowerment in their experiences with healthcare providers. They felt that this contributed to poor mental health. Trans young people’s mental health is a well-evidenced concern: a high level of self-harm and suicidal ideation is reflected in a range of studies (Capous-Desyllas & Barron, 2017; Clark et al., 2014; Fae, 2018; Katz-Wise, Ehrensaft, Vettters, Forcier, & Austin,

2018; Kuvalanka et al., 2014, 2018). However, trans young people’s mental health issues could perhaps more constructively be framed as influenced by what was described in the “Theoretical Approach” section above as “social dysphoria,” deriving from a public issue rather than a private trouble (Mills, 1959). This situates the mental distress of trans young people and their families within a framework of personal and institutional prejudice, stigma and isolation rather than as being derived solely from individual pathology (Birnkrant & Przeworski, 2017; Capous-Desyllas & Barron, 2017; Hendricks & Testa, 2012; Katz-Wise et al., 2018; Kuvalanka et al., 2018, 2014). The sense of being seen (or constructed) by doctors as a medical condition as opposed to a whole person with nuanced experience was theorized by Foucault (1975) in his explication of the undermining impact of “the clinical gaze.” The result was that both parents and children in the workshops felt that their negative experiences with healthcare practitioners had exacerbated their mental health concerns. The data points towards the need to perhaps foreground service-user voice more explicitly in practitioner interactions with children and families.

Previous research demonstrates that supportive parents of trans children tend to advocate for them across a range of contexts, including in healthcare settings, as well as home, at school, and on social media (Birnkrant & Przeworski, 2017; Kuvalanka et al., 2014; Malpas, 2011). Oliphant et al. (2018) elucidate that it is important for healthcare providers to work with parents to help them to understand their child’s gender expression, to see potential identities beyond the gender binary, and to achieve a sense of acceptance, leading to reduced anxiety and then to increased support of their child. Malpas (2011) recommends a constructive therapeutic response that involves drawing on systemic family support to help the child with their experience both at home and elsewhere -including in school and with friends and extended family. Despite this body of research, FSG participants related a wide range of incidents demonstrating how their knowledge and experience was not being taken seriously by healthcare providers. The leveraging of parental expertise (where parents are

supportive of their child's transition) and a healthy family functioning is recorded in the research literature as a crucial element in supporting the mental wellbeing of trans children and young people (Birnkrant & Przeworski, 2017; Katz-Wise et al., 2018; Malpas, 2011; Oliphant et al., 2018). Sansfaçon et al. (2019) found that the voices of transgender and non-binary children and young people and their families are crucial in developing effective treatment plans. The FSG parents suggested that their parental expertise could be better engaged in support of their children, whilst maintaining support for their own mental wellbeing. Young people are also recognized to have insights into their own lives which could be usefully deployed in healthcare settings (Carlile, 2012, 2016; Fielding & Bragg, 2003; Hart, 1992; Rudduck & Flutter, 2003). This analysis does not claim that parents know more than their child's endocrinologist about hormone treatment, for example, or that a trans twelve-year-old will know more than their GP about generalized anxiety disorder. But their insights are often a key part of the therapeutic picture, and collaborating with children and their families in their own physical and mental healthcare is established practice in many other parts of the world, including in the case of trans children and young people (Hoffman et al., 2009; Kuvalanka et al., 2014; Malpas, 2011).

Eliciting the experiences of trans and non-binary children and young people and their parents in relation to school experiences may be particularly important to developing a successful care plan. Schools were universally described as problematic by the parents and young people in the workshop. They can be difficult places for people with symptoms of anxiety or depression (or ASD- Kuvalanka et al., 2018), even without the issue of being trans. Birnkrant and Przeworski (2017) cite studies reporting victimization against trans and non-binary students perpetrated by both students and teachers in US high schools. Because of the difficulties with school, therapeutic and clinical assessments should include investigations into how school is experienced (Malpas, 2011). When children transition to the upper age groups in school the situation can become even more traumatic and complicated, partially due to a less accepting peer group more

prone to "gender policing" (Malpas, 2011). In addition, whilst primary school children will have one main teacher with whom they must build a relationship, mainstream secondary schools in the UK (for children aged 11–18) require students to walk from class to class, with a different teacher for each subject. It is possible to create a safe space at school (Birnkrant & Przeworski, 2017; Carlile & Paechter, 2018; Kuvalanka et al., 2018), and in these circumstances a therapeutic collaboration with healthcare providers could prove invaluable.

In line with UN Committee findings in the UK (Children's Right Alliance for England (CRAE), 2016), previous US-based research by Breland et al. (2016) and a review of several studies by Tellier (2019) in Canada, a gap in clinical knowledge relating to the care of transgender youth and particularly the use of blockers reportedly caused many of the current study's participating young people great mental distress. Blockers are a hormonal intervention which can slow down or pause the usual physical developments of puberty. This allows time for a child to think through their gender identity (Lynch et al., 2015; Sansfaçon et al., 2019). It can also prevent the development of unwanted sexual characteristics to improve body image and to enable a smoother physical transition process, where appropriate (Brill & Pepper, 2008; Malpas, 2011; McGuire et al., 2016; Zucker et al., 2010), although some young people choose not to transition after some time on blockers (Lynch et al., 2015; Sansfaçon et al., 2019; Zucker et al., 2010). Kuvalanka et al. (2014) interviewed mothers who had received uninformed advice from untrained health care professionals on this topic. Whilst the current study's participants noted that the long term impacts of blockers on fertility are indeed not yet fully known, they were frustrated at the lack of practitioner knowledge, and suggested that practitioners might be better served by training programs which included this content.

Further distress was experienced by the participant young people in relation to experiences of misgendering and deadnaming, often in public doctors' waiting rooms, in line with Breland et al.'s (2016) findings. Misgendering a trans patient means that they are being associated with their birth gender, and both Malpas (2011) and

Sansfaçon et al. (2019) similarly found that this can cause distress and damage potential therapeutic relationships. Previous research outlines systemic stereotyped assumptions about gender (Pearce, 2018) and sexual orientation (Brill & Pepper, 2008) by healthcare providers in England. Hoffman et al. (2009), Coker, Austin, and Schuster (2009) and Breland et al. (2016) also recommend training for healthcare practitioners in serving the specific needs of LGBTQ youth, including the use of their appropriate name and gender.

The anxiety induced by long waiting lists discussed at length by FSG participants has also been noted in previous UK studies (Children's Right Alliance for England (CRAE), 2016; Pearce, 2018). The issue is exacerbated by the fact that the clinical needs of trans children and young people are time sensitive due to the onset of puberty and associated physical changes (Oliphant et al., 2018; Children's Right Alliance for England (CRAE), 2016). Waiting lists are difficult to address (Fae, 2018). They reflect financial cuts to government funding for the NHS and mental health services in general; increases in referrals to GIDS; and the length of training people require. However, some FSG parents reported on a new approach by GIDS to offer telephone support to families of children under ten years old while they were awaiting face to face appointments. They did not feel confident that this meant their children would get an appointment before the age of ten. It remains to be seen whether these phone calls can be used to effectively triage waiting lists. Sansfaçon et al. (2019) advise triaging on a case-by case basis (delivering equality according to need) rather than offering the same wait time to each person.

The proportion of trans children and young people amongst those with ASD diagnoses may be around 7% as compared to 1% within the general population (Kovalanka et al., 2018), although because, as some parents report, the Gender Identity and Development Service may encourage screening for ASD in many cases, there may be a higher than average likelihood of the diagnosis in their children. ASD is a neurological, life-long spectrum of conditions which can involve a triad of impairments relating to social interaction; social communication, especially nonverbal; and an inflexibility of thought which can result in repeated

behaviors, rigid thinking, and a lack of social imagination (Lanou, Hough, & Powell, 2012). These issues can result in a highly developed ability to focus and to become expert on often useful skills and knowledge sets (Lanou et al., 2012). They can also result in a feeling of social isolation which is profoundly unhelpful when coupled with the stigma often familiar to trans young people (Hillier et al., 2019; Kovalanka et al., 2018). In line with research by May et al. (2017) and Hillier et al. (2019), autism diagnoses were identified by many FSG participants as bewildering their healthcare providers and slowing down their therapeutic responses to a frustrating degree. Practitioners can sometimes doubt the understanding of young people with autism to the extent that it undermines their testimony about their own gender identity and some clinicians have suggested that in a minority of these patients, gender variance could be an element of a pathological autistic hyperfocus (Hillier et al., 2019; Kovalanka et al., 2018; May et al., 2017). However, gender-variant autistic young people refute this (Hillier et al., 2019). More recent analyses suggest that young people with autism might simply be less aware of the negative judgment of others towards their gender non-normative behavior and appearance (Hillier et al., 2019; Kovalanka et al., 2018; May et al., 2017). It may be that some children and young people with ASD are "gender defiant" (May et al., 2017), or perhaps resilient to heteronormativity and cultural cisgenderism (Kennedy, 2013), and more likely to adhere to the evidential logic of their embodied experience (Kovalanka et al., 2018). Also of note is the idea, reflected in the FSG participants' experiences, that symptoms of stress and social anxiety can be mistaken for *autism* and autistic trans people who are able to live authentically have lower levels of life stress and are better able to cope with the stresses that may be associated with being autistic, including developing more satisfying and supportive friendships and school experiences (Hillier et al., 2019; Kovalanka et al., 2018). More research and training in this area is called for (Hillier et al., 2019; May et al., 2017) and this is crucial to the delivery of adequate healthcare provision for children who have ASD diagnoses and who are transgender or non-binary. In particular, therapeutic and clinical assessments are recommended to

incorporate discussions about the social and educational experiences of trans children in school (Breland et al., 2016; Malpas, 2011).

Limitations

The parents and carers involved in this project were generally positive about seeking to learn about how to best support their children in their interactions with healthcare services. The data presented here therefore excludes the experiences of families where parents are not accepting of their trans children. This is a conundrum across this field of research, and more needs to be done to elicit the experiences of families where parents are unsupportive (Birnkrant & Przeworski, 2017; Kuvalanka et al., 2014). Another limitation here is the lack of ethnic and cultural diversity amongst respondents: the majority of the participants identified as white British. In addition, the researcher is white British and Jewish, middle class and cisgender, which may have limited channels of investigation, important questions, and areas of analysis. While *Illuminate* aims to center the perspectives of the participants, their own perspectives are also limited by their characteristics and experiences. For example, participants in this study were all members of the same support group, and may have offered similar viewpoints as a result of being part of the same support-seeking organization. Because of these limitations and the fact that the number of people involved in the workshop was relatively small, the data presented here cannot be considered to be representative of all trans young people and their families in England. However, their experiences are in line with the previous international research findings referenced here, and set out an interesting range of ideas to potentially prompt or inform larger scale investigations into the experiences of trans young people and their families in relation to healthcare settings.

Conclusion and recommendations

The FSG *Illuminate* workshops unearthed some specific areas which could benefit from targeted changes in healthcare practice.

Broadly, areas for potential development include how healthcare services might better leverage the insider knowledge and extensive research conducted by parents. The support needs of parents and siblings also emerged strongly as a theme. The literature does discuss the importance of employing parental support as part of a constructive therapeutic plan (Birnkrant & Przeworski, 2017; Katz-Wise et al., 2018; Malpas, 2011; Oliphant et al., 2018). However, the participants felt that this was not in evidence in the GIDS and CAMHS services they accessed. They suggested that parents could be better supported by healthcare practitioners with their own mental wellbeing.

Better training programs for general health practitioners and specialist clinicians alike were recommended, particularly around the impact of misgendering and deadnaming, and on the implications of a trans child's experience for their family - this is also reflected in the literature (Capous-Desyllas & Barron, 2017; Coker, Austin, and Schuster, 2009; Fae, 2018; Malpas, 2011; Pearce, 2018; Tellier, 2009). Similar to research in Canada by Sansfaçon et al. (2019), waiting lists were a significant stressor reported by the families- not least because puberty proceeds along its own timeline, and long waits for treatment or universally prescribed times on specific treatments can have disconcerting physical impacts. There is therefore scope for renewed thinking into ways to triage waiting lists and treatment timetables (Sansfaçon et al., 2019). A lack of apparent practitioner knowledge - for example, on issues such as autism spectrum disorder and the long term effects of puberty blockers and future fertility- were additionally cited by the workshop participants as a source of anxiety. This points towards the possibility that healthcare practitioners in England have traditionally been under-served by their training programs when it comes to issues relating to transgender and non-binary children and young people. It may be that the increase in referrals in recent years means that training is now more likely to include this material, but an issue remains in the fact that training takes a long time to emerge into practice. This could potentially be mitigated for the time being by the production by the UK

government Department of Health of a widely distributed and easily accessible set of treatment and support guidelines in line with the world protocols produced by WPATH.

An ecological perspective which includes school, friends, and the wider community and which recognizes family expertise is also recommended in line with the literature (Kualanka et al., 2014; Malpas, 2011; Oliphant et al., 2018). Schools are more likely to feel comfortable to support trans children when they have deliberately put well-planned, robust policies and training in place (Barnes & Carlile, 2018; Brill & Pepper, 2008; Carlile & Paechter, 2018). As Malpas (2011, p. 464) asks, “If the child were to transition, would this be fully supported by the school administration? Are the primary teachers, school counselor, and staff trained to protect and empower the child in his/her ‘new’ gender expression?” The Illuminate participant workshop consensus was that teachers need more research-informed training on how to use pronouns and how to incorporate LGBT+ issues across the curriculum (Carlile & Paechter, 2018). School leaders also need more training on policy decisions around issues such as uniform and toilet provision (Barnes & Carlile, 2018). GIDS and CAMHS practitioners could play a significant role in recommending this kind of advice.

All of these ideas point towards a need for healthcare providers to take pragmatic steps to weave the voices of their patients and their patients’ families into their research and their practice; to recognize them as partners in a successful treatment or support plan, where needed; and as experts, at least on their own lives. Family members are interdependent (Cox and Paley; Minuchin cited in Katz-Wise et al., 2018), and an ecological perspective which takes family, community and school contexts into account (Kualanka et al., 2014) invites any supportive approach to working with trans and non-binary children and their families to consider them within the full range of experience. Constructive approaches to working with trans children and their families include understanding that parental coaching can be effective and empowering (Malpas, 2011). Kualanka et al. (2014) suggest that “even ‘experts’ have much to learn from

these families” (p. 371). The children and young people too have their own embodied and empirical expertise to share. It is hoped that the findings outlined here will go some way towards informing professional practice, and improving the lives of trans children and young people and their families in England.

Conflict of interest

The author declares that they have no conflict of interest.

Statement of Human Rights

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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